



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Secretary's Advisory Committee on Heritable
Disorders in Newborns and Children
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Rockville, Maryland 20857
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www.hrsa.gov/heritabledisorderscommittee

May 19, 2009

The Honorable Kathleen Sebelius
Secretary of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Sebelius:

The Advisory Committee on Heritable Disorders in Newborns and Children (the Committee) sent the attached letter to the Acting Secretary of the Department of Health and Human Services, Charles E. Johnson, on April 6, 2009. This letter details the Committee's recommendation that the Secretary initiate appropriate action to address the gaps in coverage and lack of uniformity in reimbursement of medical foods and foods that are critical treatments for children and adults identified with inborn errors of metabolism through newborn screening. The Committee desires: 1) a more uniform approach toward coverage by health care payers of medical foods and foods for those conditions recommended by the Committee and 2) specific amendments to Medicaid legislation to ensure more uniform coverage by State Medicaid programs.

Please note that the Committee's authorizing legislation instructs the Secretary to respond to Committee recommendations not later than 180 days after the Committee issues a recommendation by either adopting or rejecting the recommendation. The due date for your response is October 4, 2009. In addition, the Secretary must publicize any determination on adopting or rejecting a recommendation of the Committee, including the justification for the determination.

Effective newborn screening programs play a significant role in improving the health of our Nation's children. Please know that the Committee stands ready to be of service to you and this administration as we work together to strengthen newborn screening programs.

Sincerely yours,

R. Rodney Howell, M.D.
Chairperson